

June 25, 2016

The Honorable Governor Brian Sandoval State Capitol 101 N. Carson Street Carson City, Nevada 89701

Dear Governor Sandoval:

As chairperson of the Nevada Commission on Autism Spectrum Disorders, I am writing to update you on the activities of the Commission, as required by Executive Order.

The Commission has been reinstated by your Executive Order (2015-26). I was asked to serve as chairperson of the commission and 3 new members were also asked to serve. 1 member of the previous commission was reinstated. In keeping with the previous commission's efforts, we have continued to work on the goals of the 5 Year Strategic Plan they created. It is important to note that while the strategic plan submitted to your office had annual goals, these are ongoing and the commission will continue to work on them and adjust the time line as we move forward. In order to most effectively reach the goals set forth in that plan, new subcommittees have been created based on those goals. The new subcommittees and their associated goals as stated in the 5 year strategic plan are:

Funding and Insurance with Jan Crandy, Chair.

Maximize public and private funding sources to support the full scope of services needed for all Nevadans with Autism Spectrum Disorder (ASD). In 2016: The 2015 goal of Medicaid coverage for ABA was achieved and we are working closely with Medicaid office as the new payment plans roll forward to ensure Medicaid reimbursement rates will be sufficient to support access to services. The commission will continue to advocate for maintenance of and/or increase to state and federal funding for assessment and treatment services.

Resource Development with Jan Marson, Chair.

- Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan. In 2016: The commission will continue its efforts to put a policy in place which delivers immediate access to treatment and services based on failed autism screening. The commission will work to compile and publish service standards for children age 0-6 and 7-14 living with ASD and research, identify, and advocate for alternative approaches to providing ASD services in rural communities.

Workforce Development with Shannon Crozier, Chair.

- Expand the number and quality of professionals providing services to individuals with ASD. In 2016: The commission will continue to track and find opportunities for funding statewide Registered Behavior Technician training. Coordinate with the Department of Employment, Training, and Rehabilitation to determine how best to increase the workforce of individuals who treat children with ASD. Outreach to ASD providers for inclusion into the directory/marketplace.

Adult/Transition Services and Resources – no Chair at this time.

- Understand the needs of the ever-growing adolescent and young adult population with ASD and determine how best to meet their unique needs. Expand and develop new service plans that will provide them with the opportunity to reach their potential, live as independently as possible, and have a good quality of life. In 2016: The commission will continue to collaborate with the Governor's Task Force on Integrated Employment to advocate for and ensure that the employment needs and choices of Nevadan's with ASD, are identified, understood and addressed. Compile and publish service standards for adolescents age 15-21 and adults over the age of 21, living with ASD. Collaborate state agencies, providers and recipients to establish policies and systems which enable Nevadan's with disabilities, including ASD, to self-select their own residential setting.

Community Education with Denise Robinson, Chair.

- Promote a well-informed, empowered and supportive Nevada population around the issues of ASD. In 2016: The commission will coordinate with the Division of Public and Behavioral Health to establish and implement a statewide community education campaign. Redevelop the 100 Day Toolkit to incorporate a 365 day timeframe, to support parents and individuals in Nevada who have been diagnosed with ASD.

The Commission has met as a group 6 times since being reinstated. During that time we have met with the representatives from Medicaid, Nevada Early Intervention (NEIS), the Autism Treatment Assistance Plan (ATAP), and the UNLV Center for Autism Spectrum Disorders to better understand the current needs of our state regarding autism awareness, availability of assessment and treatment services, and

the current model for insurance and reimbursement for autism services. The Department of Health & Human Services Aging and Disabilities Services Division website specific to the Autism Commission has been updated to include all relevant information regarding the changes in the Commission and its activities.

Nevada's Autism Statistics and Highlights as reported to the Commission since March 2016:

7,334 children with ASD in Nevada (based on data from NEIS and Dept of Education)

Medicaid:

• 24 Medicaid claims for ABA were submitted

ATAP

- 657 total children served by ATAP
 - o 3 are under 3 years
 - o 173 are 3-5 years
 - o 205 are 6-8 years
 - o 139 are 9-11 years
 - o 137 are 12-18 years
- 581 children on ATAP waiting list; average age 7
- 53 new applications per month on average for ATAP services in 2016
- 236 days on average a child will be on the ATAP waiting list
 - o 76 children under 3 years on waiting list
 - o 299 children 3-8 on waiting list

NEIS

- 234 children with ASD served by NEIS
- 137 children diagnosed with ASD during this fiscal year
- 30.7 months is the average age at which a child is diagnosed with ASD in NEIS

The Commission is proud to recognize and applaud our State for the ongoing additional funding to address the needs of individuals with autism, to improve our education system, and the legislation passed during the last session to support individuals with ASD and disabilities.

We believe our State has made great strides to improve access to treatment and in some ways is a leader nationally in this area. However, there continue to be important concerns and obstacles to address the needs across the lifespan of all Nevada individuals and families affected by ASD. The commission sets forth that the most important of these include:

- 1. ATAP's decision to require all treatment providers as of July 1, 2016 have a certain level of training (Registered Behavioral Technician (RBT)) in order to be reimbursed for services. While this will help ensure that children receive the highest level of treatment in the long run, it will create a serious obstacle to receiving services in the short term due to the sobering lack of services providers who meet these requirements. ATAP has wisely allowed providers who are currently serving children and who may be hired in the future, but do not meet the minimum training, 6 months to become certified. Cost, time, and difficulty finding adequate training programs make this difficult.
- 2. ATAP, as of July 1, 2016 will begin transferring funding of services of Medicaid eligible children to Medicaid. ATAP reports that 55% of their children are Medicaid eligible (361 children). At this time there are not enough Medicaid enrolled BCBAs to supervise, or RBTs to treat, 55% of ATAPs caseload. To provide just this number of children with a basic level of services, it is conservatively estimated that 165 BCBAs/BCaBAs and 1952 RBTs will be needed. As of May 2016 Nevada Medicaid had enrolled 22 BCBAs/BCaBAs and 64 RBTs.
- 3. ATAP has opted to eliminate the option for a family to hire their own service provider.
- 4. Managed Care and Medicaid's current rates of reimbursement for the delivery of ABA may be too low to encourage current providers to enroll as Medicaid providers. Some providers are already transitioning children out of their care as they feel the determined rate makes it impossible for them to continue providing services and meet their expenses.
- 5. Managed Care and Medicaid's current rates of reimbursement for the delivery of ABA may be too low to attract new providers to our state to ease our overwhelming shortage.
- 6. Ongoing insufficient workforce and staffing issues for autism programs to meet current needs; compounded by ATAP changes and Medicaid reimbursement rates.
- 7. Lag between initial concerns, identification (failed screen and diagnosis) and access to evidence based levels of treatment; especially in those under 3 years of age.
- 8. Assessment and services disparities for critical populations including rural/remote locations, racial/ethnic groups, and low socioeconomic status.
- Lack of services, funding, and supports specific to young adult ASD population needs which support self-determination including transition

- services, housing, and pre-vocational and vocational training funding to allow for meaningful employment.
- 10. Medicaid's lack of coverage for evidence-based treatment specific to ASD (ABA) for individuals over the age of 21

The commission has recently made recommendations to the Legislative Health Care Committee to address some of the above concerns. Our recommendations included:

- 1. ATAP continue to allow payment to interventionists working under the supervision of a BCBA, without requiring an RBT credential, until there is an RBT workforce ready to serve a minimum of 50% of the children enrolled in ATAP and Medicaid that reside in Rural, Southern, and Northern Nevada.
- 2. For the time being, ATAP continue to support the policy allowing parents to be the employer of record for their child's interventionists with the assistance of an ATAP provided fiscal agent.
- ATAP delay the transfer of ATAP Medicaid-eligible children to Medicaid until
 there is a Medicaid provider ready, willing and able to seamlessly accept and
 provide medically necessary and evidence based levels of treatment to the
 child.
- 4. ATAP continue to ramp up its efforts to serve children directly as a Medicaid provider, utilizing the children's current interventionists as much as is practicable.
- 5. Expand efforts and funding to grow our BCBA, BCaBA, and RBT workforce through our higher education system and encourage DETR to include the BCaBA and RBT training, internship and certification in their programs and scholarships.
- 6. Improve collaboration between NEIS, ATAP and Medicaid to allow children under 3 years of age a fast-track to accessing ABA programming at recommended levels.

Future reports will be formatted based on the 5 year strategic plan goals and work of each of the subcommittees that aligns with each goal area. This report is meant as an overview as this new commission begins moving forward.

We appreciate the valued support we receive from ADSD staff and your Chief of Staff. Because of your support, children with ASD have the hope of reaching their real potential. The members of the Nevada Autism Commission thank you for your ongoing and valuable support. We are grateful for and trust you have shown in us and this commission by renewing the Executive Order which has allowed the commission to continue to function. The commission and it's subcommittees will

continue to work on ways our state can lead the way in it's care of individuals with ASD in the most effective and efficient manner so that all Nevadans living with Autism Spectrum Disorder will achieve optimal outcomes to reach their full potential.

If you have questions, my contact information is (702) 992-6847 or Mario.gaspardelba@unlv.edu.

With hope and gratitude,

Mario J Gaspar de Alba, M.D., Chair